



SPECIAL NEWS FOR SPECIAL NEEDS



Issue 3

Spring, 2003



Snow flurries in April? It is hard to believe this is supposed to be springtime! Hopefully the worst is over and we can enjoy the beautiful flowers starting to peek through the ground. In the meantime, sit back and take a few minutes to read this expanded issue of *Special News for Special Needs*. We have some great new websites and we're offering a six-week parenting series designed especially for families of children with special needs. We've also added a new section, "Ask the Doctor" -- great information from Dr. Carol Owens, our Child Development Watch pediatrician. And, we have a section on transition, an important topic for all families. This is our third issue and we continue to look for ways to improve our newsletter so it meets the needs of our families. Please feel free to call me at 302-422-1335 or 800-752-9393 with your ideas and suggestions. You can also reach me on e-mail at sward@state.de.us. Looking forward to hearing from you.

Sandy Ward

Family Support Specialist



MAILING LIST



Please help us keep our mailing list updated. If you are currently receiving mailings from us and would like to discontinue receiving them, please call Sandy at 422-1335 or 800-752-9393. If you would like to receive our mailings (especially the newsletter) via e-mail, please call or e-mail Sandy with your e-mail

PARENTING SERIES

Please join us for a six-week Parenting Series featuring Yvonne Naas of Child, Inc. This series is specially designed for families of children with special needs. Discussion topics will include Behavior and Discipline, Coping with Stress, Improving Self-Esteem and Parenting Skills. We will meet on Monday evenings (May 19, June 2, June 9, June 16, June 23 and June 30). Each session runs from 6:15 p.m. to 8:30 p.m. in Room 207 of the Grier Bldg., Bayhealth Medical Center (Milford Memorial Hospital). Certificates of completion are awarded to parents at the conclusion of the six-week series. There is no charge and childcare is available upon request. Pre-registration is required and class size is limited. Please call Sandy Ward at 422-1335 or 800-752-9393 and register today. (See flyer in this mailing for more details.)



Are you a Senior Raising Kids?

If you are 60 years of age or older and raising your grandchildren or the children of relatives, call your local YMCA (674-3000/Dover, 227-8018/Rehoboth) and inquire about their Summer Camp Respite Program. Cost decided individually on a sliding fee scale basis.



Delaware Health and Social Services, Child Development Watch



Check out
these great
websites!



- www.schwablearning.org/articles.asp?g=2&r=684
Information regarding possible tax deductions/credits that might be available to parents of children and adults with disabilities.
- <http://school.discovery.com>
Great site for parents who want to help kids with schoolwork.
- www.EFMconnections.org
Department of Defense launched a new website designed to give military families with special needs access to information on a variety of military, federal and local programs available.
- www.cffde.org
Children & Families First is a private, non-profit agency that strengthens families and communities by providing quality social, educational and mental health services.
- www.picofdel.org
Parent Information Center of Delaware (PIC) is a private, non-profit organization that provides information and support for families who have a child with special needs. PIC offers workshops on accountability, advocacy, communication, special education law, and much more.
- www.poweroftheordinary.org
Power of the Ordinary Online is a celebration of the rich array of powerful learning opportunities occurring throughout the everyday lives of young children ages birth to six.



I love to read!
Check out these
great books!

GROW WITH BOOKS is a special collection of books for special kids and the special people who love them! These books are specially designed for children with (or at risk of) a disability or a developmental delay. There are also great books for grown-ups in this collection. Call or visit your local public library to see the collection for yourself or call Sandy at 422-1335 or 800-752-9393 and she'll send you a listing of the books.

ASK "DR. O"

Dr. Carol Owens

Child Development Watch Pediatrician

- Q.** Is newborn hearing screening required by law in Delaware?
- A.** Not by law, but Delaware has an Early Hearing Detection and Intervention Program that screens all infants by 3 months of age. All hospitals in Delaware have the equipment in place to do this screening. Records will be kept in a central data bank so no child will be lost to follow up.
- Q.** How many children can be expected to have hearing loss in the newborn period?
- A.** Nationwide estimates are anywhere from 1-3 per thousand for all infants and up to 56 per thousand for high-risk infants are expected to have hearing loss. Put another way, 33 infants are born each day with hearing loss significant enough to impair speech development.
- Q.** What are some of the conditions placing an infant at high risk to have hearing loss?
- A.** Examples of conditions contributing to high risk for hearing loss can include (among many others): in-utero infections such as cytomegalo virus or rubella, high bilirubin which requires an exchange transfusion, respiratory distress (especially if support on a ventilator or ECMO was needed), cleft palate, several genetic diseases such as Down syndrome, Turner syndrome, mitochondrial or mucopolysaccharidoses, and persistent middle ear fluid for at least 3 months.
- Q.** How can you tell if a baby can't hear?
- A.** Several tests have now been developed which don't require the infant or child to indicate they can hear a sound. These are ABR or automated brainstem response testing, and OAE or otoacoustic emission testing. These are screening tests. If these are not passed, other more detailed testing is used. Parents can also be aware of baby's responses such as being calmed by mother's voice by 3 months, showing interest and attending to musical toys by 6 months, imitating and playing with speech and non-speech sounds by 6 -9 months, understanding "no" and "bye-bye" by 12 months. Hospital staff provide a language and hearing checklist to parents of newborns.
- Q.** Can infants be fitted with hearing aids?
- A.** Yes, and this should be done by 6 months if a hearing loss is identified. This should be done by an audiologist licensed by the State.
- Q.** Where can I find out more about the Delaware Newborn Screening Program?
- A.** The contact number for this program is 302-744-4551 or 800-262-3030. Ask for the Hearing Screening Coordinator.



**Rose are red
Violets are blue
I'm glad to be on
This earth with you.**

by Lizzy MacDonald, age 8, 1997

This is a poem my daughter Lizzy wrote when she was about 8 years old. You are probably thinking that it is just a cute little poem. You are right. What you don't know is that my daughter wrote this shortly after her grandfather died and just after she found out she was about to have her second cervical spinal fusion. Lizzy was celebrating her life even as she anticipated a seven-month ordeal wearing a metal halo ring with pins in her skull and a full body cast to support it on her tiny 28" tall body.

Lizzy's poem was finally taken off my refrigerator after 2 years and placed with many other keepsakes.

Lizzy is now 13½ years old and ready to begin 9th grade next year. It seems only a few years ago when she was on a ventilator and feeding tube in the hospital. Then my biggest concern was getting her home for her first birthday. Six surgeries and 10 months later, Lizzy came home in an ambulance. As the first infant in Delaware sent home on a ventilator (breathing assistance machine), Lizzy had 24 hour nursing care and a parade of therapists to provide services.

The next few years were filled with constant trips to the hospital by ambulance and helicopter. By age 4, Lizzy had just learned to take enough food by mouth to allow us to stop using her feeding tube. She still had nursing care 18 hours each day, which she would desperately need after her next spinal fusion.

At age 5 Lizzy was ready for kindergarten, but she still had her tracheotomy. The July before she was to begin school, Lizzy breathed without an artificial airway for the first time since she was a month old. Most folks we knew were very excited for Lizzy and our family. Oddly enough, Lizzy and I were afraid. It would be very scary to experience life together without the support of an artificial airway. This fear manifested itself in two ways. As we arrived at the hospital on July 4, I began by locking the keys in the van at the Ronald McDonald House. Lizzy showed her fear by spiking a temperature which delayed the procedure. Finally, after two days, Lizzy was without an artificial airway. I always thought it rather interesting that this procedure was scheduled on Independence Day.

School began in September with Lizzy and her para-professional breaking new ground and making friends with almost everyone. Lizzy used a walker in the classroom and a small tricycle to travel in the hallways. Kindergarten was a new experience for all of the children so Lizzy just became a normal part of their kindergarten life.

Our next step was to order a wheelchair. I had heard parents talk about how difficult that was, as if it were a beacon to the world shouting "My child won't walk like other children." Getting the chair was not as painful as I thought. Perhaps that was because Lizzy was so darned thrilled about it. The first time she used her manual chair, she maneuvered it like she had been doing it her whole life.

Eight years later, Lizzy continues to participate in all regular education classes on the same level as other children her age.

Yesterday I was reminded of Lizzy's poem.

Roses are red
Violets are blue
I am glad to be on
This earth with you

Nothing specific triggered the reminder, but rather the everyday challenges Lizzy faces to get out the door for school.

Here's a typical schedule:

- Liz gets up at 5:30 a.m. to rest while she has her morning breathing treatment (30 minutes).
- Liz gets her glasses and watch and scoots to the end of her bed and climbs down a step to the floor.
- She scoots to the top of the stairway. (3-4 minutes)
- Liz scoots down the stairs step by step on her bottom. (2-3 minutes)
- At the bottom of the stairs Lizzy picks up her crutches and walks to the bathroom. (2 minutes)
- Liz has to move her wooden steps up to the toilet. (bathroom time 7-10 minutes)
- Liz has help getting in and out of the bath, with bathing, hair, teeth, and getting dressed. (10 minutes)
- Liz is carried to her stool, gets her crutches and walks to her chair and table for breakfast. (breakfast 15 minutes)
- Shoes and coat. (5 minutes)
- Liz uses her crutches to walk to the door and is lifted down the steps to the garage where she walks to her wheelchair. (5 minutes)
- The bus is here! This is the bus everyone in our neighborhood rides.
- Liz rides up the lift and is carried to a special child seat belt seat in the front of the bus. (5 minutes)

I remembered the poem. I remembered when I was 13 years old, and how I just got out of bed, got dressed and ran out the door to school. My daughter Lizzy will never be able to do things that easily.

I remembered the poem and thought about Lizzy's spirit and how she takes on every challenge and loves the world.

I remembered the poem and how grateful I was to have the author as my child and a part of my world.

Beth MacDonald

Parenting Series

Offered by Early Intervention FAMILY FORUM
Delaware Health and Social Services
Part C Birth to Three System

This free six-week parenting class is designed for families of children with special needs.

WHEN: Six Monday Evenings
May 19, June 2, June 9, June 16, June 23 & June 30, 2003

TIME: 6:15 p.m. – 8:30 p.m.

WHERE: Room 207, Grier Bldg.
Bayhealth Medical Center (Milford Mem. Hospital)
21 West Clarke Avenue, Milford

SPEAKER: Yvonne Naas, Child, Inc.

TOPICS: Behavior & Discipline, Parenting Skills, Listening Skills, Self-Esteem, Emotions, Coping with Stress

TO REGISTER YOUR ATTENDANCE, PLEASE CALL SANDY WARD AT 422-1335 or 1-800-752-9393. PREREGISTRATION IS REQUIRED. CLASS SIZE IS LIMITED.



TRANSITION...



What is transition?

The term transition is used to describe the movement of a child and family out of one program or environment into another.

Transition is a process, not a single event. Transition involves change for families and children as well as the agencies that serve them. Effective planning for changes can help ease the stress for everyone involved.

Transition planning will help enable you and your child to receive continuous care and services. It establishes communication among agencies, service providers, and families. Good communication enhances the family's ability to have input and make informed decisions.

At the time your child turns three years of age, he/she may be eligible to receive services within their school district if the child's developmental needs are related to the child's ability to learn. This may include service delivery in community placements, schools, homes, etc. The long-term goal of transition is to move your child more and more into the mainstream of your community.

At CDW, we recognize that the process of transition may be a time of stress and confusion. Therefore, it is our goal to be actively involved in the process so transitions can be positive and productive. This includes having a timely transition conference.

What is a transition conference?

A transition conference is when the family, service coordinator, school district representative and others you invite discuss your child's needs and how those needs can best be met when your child leaves Child Development Watch at about three years of age. This conference may be held at your home, a school site, a Child Development Watch site, or on the telephone. At this conference, the transition plan section of the IFSP is completed. The plan outlines the steps that your family, service coordinator, providers, and school district, if applicable, will take to make a successful transition.

Some Questions to Think about for the Transition Conference:

- **What are my hopes and dreams for my child?**
- **Where does my child learn best?**
- **Who can we call if we have questions?**

(Con't)

TRANSITION... (Con't)

At the Transition Conference:

Your family can:

- **Share your hopes and dreams for your child**
- **Participate in the transition process at the level that feels comfortable for you**
- **Ask questions about things that may be unclear to you**

Child Development Watch Service Coordinator will:

- **Share information about your child's progress**
- **Help write a transition plan with specific steps for transitioning**
- **Help you identify additional community resources and supports**

Service provider will:

- **Explain the needs of your child**
- **Describe present services, goals, and progress**
- **Discuss their experience with your child and how the child responds in other settings**
- **Discuss the end date for current services**

School District representative will:

- **Explain your child's rights and your rights as a parent**
- **Explain what determines eligibility for school district services**
- **Plan the next steps that lead to eligibility determination and development of the individual educational plan (IEP)**
- **Describe how the needs of your child are likely to be addressed**

What is my role as a parent?

Remember, as a parent you are the expert on your child! You are an important team member. Decisions about your child are made with you!

